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The financial implications for parents of the death of a child

Little is known about the financial impact of a death. When a child dies from a life-limiting condition, the family's income can be significantly reduced because of loss of or reduction in benefits. At the same time, there are funeral expenses. Researchers at the University of York have carried out the first in-depth study of the impact of the death of a child on the financial circumstances of 17 families.

f All parents felt the impact from loss of or reduction in benefits. This could result in an immediate drop in income of as much as 72 per cent, in the case of a lone parent who was not doing paid work.

f Funeral costs were a common cause of difficulty and the cost of headstones was an additional expense.

f Financial problems which arose following the child's death were also related to financial aspects of the period of care. Significant reductions in income, associated with reducing or leaving paid employment, and the extra costs of care meant that some families had got into debt. Patterns of expenditure during a child's life took time to change.

f Moving back into employment was difficult for those who had given up paid work to care for the child. Some employers saw the time spent caring as a gap in CVs and some questioned parents' reliability. For parents whose last or only child had died, the requirement to register for work eight weeks after the child died seemed harsh.

f For some, the withdrawal of benefits seemed like society's acknowledgement that their child's life was over. The way in which this was dealt with was important and insensitive treatment increased pain and grief.

Background

The financial impact of a death is rarely discussed in literature on bereavement support. This study arose from concerns expressed by staff at a children's hospice that, for some families, the period following the death of their child is one in which they face significant financial problems. In turn, these problems can affect the healing process after bereavement. Hospice staff pointed to a number of issues which affected many of the families they served. These included: the cessation of some benefits; the impact of low parental income, often associated with problems in resuming or starting paid work; the impact of spending patterns established during the final months of the child's life, which take time to adjust to changed circumstances; the cost of funeral arrangements; and, for some, the effects of debt accumulated during the period of care.

This study explored the experiences of 17 families whose child had died in the last two years, and who had been in touch with the local children's hospice. Health, social services and hospice staff were also interviewed, and staff in other children's hospices and bereavement services completed questionnaires.

The cost of caring

The ways in which families' financial circumstances were affected after the death of their child were strongly influenced by their situation whilst caring for the child. All the families had been caring for a child with a life-limiting condition; many parents had been providing high levels of care for many years. During this time, they had had to manage household spending and decide whether to do paid work, knowing that their child's life was likely to be limited, but not knowing how much longer he or she would live.

Employment

Parents made different decisions about doing paid work during their period of caring, depending to some extent on the pattern of development of their child's condition, the support they received from services in caring for the child, the attitudes of their employers, and what stage they were at in their family life. Some parents experienced significant reductions in income, associated with reducing their hours of work or leaving paid employment. Two-parent families sometimes had more opportunities than lone parents for working while their child was ill and keeping a job to return to after their child died. None of the lone mothers interviewed had been able to do paid work during the final years of the child's life.

Extra costs

There was a general need to spend extra, often accompanied by a reduction in income. Fuel bills were high because of a need to keep the house warm at all times, heavy use of washing machines, tumble-dryers and other electrical appliances, and, in many cases, the need for power for technological support machinery, such as ventilators. Parents saw no scope for reducing high fuel bills.

There was often heavy use of the telephone, to keep in touch with caring staff and to co-ordinate home services, as well as for emotional support from family and friends. Transport was a significant expense for some. Frequent trips to hospitals and specialist centres, and, in some cases, the need to transport bulky equipment meant that families relied on having a dependable vehicle. Clothing and bedding for the child, equipment and house adaptations, and costs associated with hospital stays all added to families' expenditure.

Knowing that the child may not have much longer to live, some families took all opportunities for outings and holidays whilst this was still possible. Priorities for household spending were set to what was wanted at the time, and for some this meant using up savings, increasing overdrafts or credit, or seeking loans or charitable funds.

Benefits and allowances went some way towards, but rarely compensated for, reductions in earnings and extra costs. Families made different spending decisions and had different aptitudes for managing their resources. Some received help from relatives, and some had access to grants from charities. While some parents felt that money was not a pressing problem while they cared for their child, others had lived through several years of financial constraint; some had got into debt and felt that financial matters were out of control by the time their child died. It was not always those parents with the lowest incomes who felt most stressed financially. Stability of income, full take-up of benefits, financial support from relatives, and timely and efficient delivery of aids and equipment from care services were among the factors which could enable parents to avoid financial problems.

Loss of benefits following the death of the child

Whether or not parents were already facing financial problems when their child died, all parents then felt the financial impact from loss or reduction in benefits. This had been a shock to some. They had known that they would lose benefits, but had not

anticipated the amount or immediacy of the reduction. As an example, in a two-parent family with a father who had continued in paid work and earned around £18,000 gross per annum, loss of disability living allowance, child benefit and invalid care allowance meant a reduction of 25 per cent of net monthly family income. A lone parent caring for a teenage son - with a weekly income made up from income support, child benefit, disability living allowance and invalid care allowance - had an immediate reduction of 72 per cent in the money available for household spending. Such a big drop in income felt like an added blow, and required rapid readjustment for which parents were not well-equipped emotionally at this time.

Funeral expenses

Funeral costs were a common cause of difficulty. Costs varied widely depending upon the kind of funeral wanted, but it was not always possible to keep costs low, even with a simple funeral. Parents who wanted headstones had an additional bill. For some, it meant further borrowing or applying to charities. In the experience of staff, families who had the most difficulty in paying for funerals were those whose income meant they were just beyond eligibility for a Social Fund grant.

Moving to new patterns of income and expenditure

At the time of the interview, all the parents were moving to new patterns of income and expenditure. Parents had different employment opportunities and expectations in the months following their child's death. Those who were formally employed when their child died went back to work after the funeral. It could be hard to do this at a time of profound family grief, but in retrospect, those who had maintained a strong 'breadwinner' role during the child's final illness and returned to work soon afterwards felt they had taken the right decision. Parents whose return to work had been driven by financial necessity rather than commitment to a job or an earning role all felt that they had gone back to work too soon. They did not get on well at work, even in work they had previously enjoyed.

Parents who had been claiming income support had no jobs to return to. Thinking about getting work and finding a job could be hard at this stage. Even highly motivated parents did not get work quickly. Years spent caring for a child were gaps on CVs and some employers doubted that they would be committed or reliable.

For some parents, even thinking about their future in terms of work was stressful. Parents claiming income support, whose last or only child had died, had little time to adjust. Eight weeks after their child died came the requirement to make themselves available for work to continue receiving jobseekers' allowance. This had not always been anticipated and could be a shock. Some parents obtained sickness certification from GPs. 'Bereavement' is not an acceptable medical condition for entitlement to incapacity benefits, so some parents acquired medical labels of depression or anxiety. Some described their current situation as a 'trap' in which, as incapacity benefit claimants, they were not required to look for work and received no help in doing so. Some of those who did go back to work then discovered that a period of caring had led to interruptions in their National Insurance record such that they could not claim contributory benefits if they became unemployed or needed sick leave.

Longer-term financial adjustments were hard for other reasons. Patterns of expenditure established during the child's life took time to change, fuel bills incurred during this time continued to arrive, large adapted vehicles were expensive to run but hard to sell. Trying to take the edge off grief or finding ways of filling long, empty hours had led some parents to spend heavily in the months following their child's death.

Emotional impact of financial matters

The withdrawal of benefits had an emotional impact due to the loss of what the benefits represented. The immediate end to child benefit and disability living allowance could seem like society's formal acknowledgement that their child's life was over, accentuating the pain. Similarly, the end of their invalid care allowance could seem like a formal mark that their 'caring' or parenting role was over, underlining the void in their lives. Yet there was no acknowledgement of the importance of their role and the contribution they had made.

Policy and practice implications

The findings provide some important pointers for policy consideration. Finding ways of softening the impact of immediate cessation of benefits and finding ways of protecting the NI record of all parents caring for a very sick or disabled child are structural social security matters, the responsibility of government and DSS. Providing opportunities for parents whose child has died to have easy and timely access to appropriate information and support on

employment options is of interest to policy-makers currently developing welfare-to-work initiatives. Supporting parents to maintain employment when their child is seriously ill is important in helping parents to avoid financial problems; consultation on whether to increase parental leave available to the parents of disabled children, as part of the Government's Green Paper on 'Work and parents', is an important step forward.

When the end of a benefit has profound emotional significance, the way this is handled becomes extremely important. Parents remembered the words used in the administrative letters notifying them of the end of benefit, and had many suggestions as to how pain might have been reduced during this interaction. Parents wanted the letter to acknowledge their sadness; to use their child's first name; and to say that their child had died, not that s/he was deceased.

These findings raise questions about where responsibility might lie for helping parents deal with financial matters, and how far some of the problems might be avoided, or prove easier to resolve, if parents were enabled to think about the issues in advance of the child's death. Finding ways of helping parents to think ahead is not easy, and it seems likely that responsibility must be shared across different agencies and organisations. It may not be hard for government agencies to make available information and advice about benefit situations and employment opportunities for bereaved parents, but the expertise in supporting parents in thinking about such matters while their child is alive probably lies elsewhere, and may be rather scarce.

Finally, the study raises the question of whether there should be a place for 'money' as a topic in bereavement counselling and how bereaved parents can be helped to deal with financial and employment matters, which are complex in terms of practical decision-making, but which also have profound psychological significance.

About the study

The study comprised three elements:

- Interviews with parents in 17 families who had been in touch with a local children's hospice; in most of these families a child had died during the last two years.

- Group discussions and interviews with key staff in health and social services, and in the hospice.
- A postal survey of all children's hospices and a number of bereavement and support groups for parents.

The ages of the children when they died ranged from one to 17 years. They had a wide range of conditions, including metabolic diseases, chromosomal abnormalities, progressive neuromuscular disorders, and childhood cancers.

How to get further information

The full report, **Financial implications of the death of a child** by Anne Corden, Roy Sainsbury and Patricia Sloper, is published for the Foundation by the Family Policy Studies Centre (ISBN 1 901455 41 6, price £10.95).